

## **POSITION DESCRIPTION: Director of Development, The CFIDS Association of America, Inc.**

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### **Overview**

Client: The CFIDS Association of America  
Location: Charlotte, NC  
Founded: 1987  
Employees: 5  
Reports to: CEO

### **ORGANIZATIONAL DESCRIPTION**

#### **History:**

The CFIDS Association of America is the nation's leading charitable organization dedicated to conquering chronic fatigue and immune dysfunction syndrome (CFIDS), also known as chronic fatigue syndrome (CFS) and myalgic encephalomyelitis (ME). Based in Charlotte, NC, the Association was founded in 1987 by Marc Iverson. After falling suddenly ill in 1979, Marc spent seven years in search of an explanation for the bizarre and life-altering symptoms; he was diagnosed with CFS in 1986. This odyssey led him to crusade for better understanding of CFS and more research on the disease.

Today CFS remains a debilitating illness with no known cause, diagnostic test, or universally effective treatment. It often begins with a sudden onset of flu-like symptoms with persistent lack of stamina, brain fog, widespread body pain and weakness and intolerance of upright posture. A relapse of all symptoms after even modest physical or mental effort is the hallmark of the conditions. More than a million adults, teens and children in the U.S. have the illness with an estimated 17 million cases worldwide, although only 10-20% of people with CFS have been diagnosed. The impact on the individual and family is huge and CFS results in a loss to the U.S. economy of about \$30 billion each year.

The Association offers information and resources to people living with CFS, family members, health care professionals, researchers and the general public, but its primary focus is to lead efforts aimed at identifying disease modifying treatment for CFS. Through the [Research 1<sup>st</sup>](#) website and newsletter, the Association provides the most current and reliable information about CFS-related research being conducted by top-flight scientists worldwide.

To learn more about the Association's accomplishments and goals, please review the following link from FasterCures: <http://www.fastercures.org/train/CCC/spot.html>.

#### **Milestones:**

Over the past few years, the Association has ramped-up its efforts to focus on clinical research and raise capital to fuel those activities, including:

- **SolveCFS BioBank:** In 2010, the Association established the first patient-centered integrated registry and biorepository for CFS with infrastructure support provided by the Genetic Alliance BioBank. Individuals with CFS, family members and healthy controls aged 10 and older from the U.S. and other countries can now participate as active stakeholders in CFS research through the SolveCFS BioBank. This important research resource provides laboratory researchers with access to a well-characterized clinical population they would otherwise be challenged to reach.
- **The Catalyst Fund:** In the summer of 2011, the Association announced the creation of this fund, established to speed discovery and transform the way that CFS research is conducted. As a major gift

strategy, the fund attracted considerable lead investment and is a centerpiece of future efforts. Donors at all levels of giving are recognized as [Catalysts](#) who speed progress.

- The Research Institute Without Walls (RIWW): In 2012, the Association launched eight research projects organized under [the RIWW](#) – a groundbreaking effort to facilitate tightly integrated, expert-led research project all pointed to one goal: To advance objective diagnosis and effective treatment of CFS. At the core of the RIWW is the SolveCFS BioBank and researchers are linked through a secure data-sharing platform, creating a virtual institute that leverages leading experts at top institutions working on projects of high scientific and strategic merit.

In support of these activities, the Association has also recently undertaken a rebranding initiative to highlight its narrowed focus and highlight its innovative approach. The Association engaged NYC-based “brandraising specialist” Big Duck to conduct an initial assessment and will be resourcing an effort to rebrand the Association as a patient-centered research-driven nonprofit fueled by community support and investment.

The Association is seeking a Director of Development to drive the raising of contributed revenue to support critical research efforts through a multi-faceted fund development plan that focuses on seeking major gift support (The Catalyst Fund) while also driving broad engagement and support. The Association has secured external counsel (Patton McDowell & Associates) to assist with the creation of a fund development platform and to lead the search for a new Director of Development.

#### **The Role:**

Responsible for developing and implementing all aspects of the CFIDS Association of America’s development program, the Director of Development will report to the President & CEO, and will have the unique opportunity to help build and lead the Association’s fund development effort during a period of exciting change, rebranding and growth.

#### **Volunteer Relations and Planning**

- Creates annual development plan and calendar of fundraising activities (90-day articulation) in conjunction with input from CEO and Development Committee of the Board of Directors.
- Creates strategies for development plan execution focused on donor engagement at multiple levels, individual major gifts, foundation relations and grantmaking opportunities.
- Implements a form of “moves management,” encouraging greater engagement from initial awareness to first gift and beyond.
- Works with CEO and Development Committee on long-range planning.
- Coordinates Development Committee meetings and facilitates with CEO.
- Prepares materials, statistics, data analysis and other information for development reports and to support future planning.
- Coordinates with non-board volunteers on regional fund development planning.

#### **Prospecting and Data Management**

- Serves as conduit for board members to identify potential sources of support, both financial and volunteer.
- Maintains database records on current prospects and donors, ensures the successful management of the donor database.
- Conducts secondary research and segments database to identify gift prospects (individuals and foundations) and develops timeline and structure to facilitate communication.
- Creates and maintains prospect profiles for staff and volunteer leadership

#### **Fund Development and Management**

- Manages implementation of development plan, including:
  - Major gift cultivation, solicitation and stewardship.
  - Annual fund messaging, solicitation and acknowledgement.
  - Support for constituent-led fundraising events.
  - Foundation grant proposals.
- Develops case for support language and material for diversified constituencies.
- Supports national outreach activities, including cultivation events in selected markets (including San Francisco, Denver, Chicago, Charlotte, New York City, Washington, D.C., and Los Angeles) Some travel required.
- Conducts face-to-face cultivation and stewardship with major and lead gift donors, as well as constituents engaged in regional fundraising efforts.
- Generates acknowledgement letters and conducts donor-related administrative activities.

### **Qualifications**

The ideal candidate would have the following capabilities and qualities:

- Bachelor's degree is required.
- At least 7 years professional fundraising experience; fund development experience in health organizations or experience with CFS specifically preferred.
- Understanding and passion for the Association's mission.
- Strong interpersonal communication skills; high-energy, proactive, entrepreneurial self-starter with the disposition to work in a small office environment.
- Team player who will be a collegial partner to staff, constituents and external stakeholders.
- Proven writing, editing and oral communication skills.
- Tech savvy, proficiency with Microsoft Office suite and ability to perform administrative detail
- Experience with database updating and management required, Convio CRM experience a plus.

### **To Apply**

The CFIDS Association of America is an Equal Opportunity Employer committed to inclusive hiring and dedicated to diversity in its work and staff. Employment decisions at the Association are made without regard to race, color, religion, gender, sex, national origin, physical or mental disability, age, sexual orientation, veteran status, or any other characteristic protected by applicable state or federal law. The Association encourages candidates of all groups and communities to apply for this position.

Beginning July 2, all inquiries, nominations and applications are to be directed via email to Patton McDowell & Associates: [search@pattonmcdowell.com](mailto:search@pattonmcdowell.com). Applications should include a cover letter and resume. Please indicate in the subject line of your email the position and organization to which you are applying and where you learned of the opportunity. NO PHONE CALLS PLEASE.

Please note that only those candidates invited for screening will be contacted.